



UNITED  
CEREBRAL  
PALSY  
ASSOCIATIONS

*Advancing the independence of people with disabilities*

**May 3, 1996**

**Office of the Secretary  
Federal Communications Commission  
1919 M Street, N.W.,  
Washington, D.C. 20554**

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**MAY 3 1996**

**FEDERAL COMMUNICATIONS COMMISSION  
OFFICE OF SECRETARY**

**In the Matter of Federal-State Joint Board on Universal Service CC Docket No. 96-45** **DOCKET FILE COPY ORIGINAL**

Enclosed please find an original and five copies of United Cerebral Palsy Associations (UCPA) Reply Comments in this matter.

For the Federal-State Joint Board  
on Universal Service  
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Before the  
FEDERAL COMMUNICATIONS COMMISSION  
Washington, DC

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In the Matter of  
Federal-State Joint Board  
on Universal Service

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CC Docket No.

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MAY 3 1996

FEDERAL COMMUNICATIONS COMMISSION  
OFFICE OF SECRETARY

May 3, 1996

**UCPA's Comments In Reply and In Support of the Comments Made by the American Foundation For the Blind (AFB) on the Notice of Proposed Rulemaking Regarding Federal-State Joint Board on Universal Service and Urging of the Inclusion of Issues of Access by Persons With Disabilities As a Factor in Development of Universal Service Principles**

To the Commission:

United Cerebral Palsy Associations (UCPA) appreciates this new opportunity to offer Comments concerning FCC proceedings on Universal Service as invited in the *Notice of Proposed Rulemaking on a Federal-State Joint Board on Universal Service* (Federal Register, March 14, 1996).

UCPA continues the discussion begun in our Reply Comments submitted in Docket No. 80-286, of December 2, 1994, concerning the FCC proceeding in the matter of Amendment of Part 36 of the Commission's Rules and Establishment of a Joint Board. [Our December comments are attached as Appendix I, Parts A, B and C]. At that time we noted that inclusion of the needs of individuals with disabilities had been omitted so far in the discussion and we are pleased now to see the discussion broadened as a result of enactment of P.L. 104-104, The Telecommunications Act of 1996. This Act includes provisions addressing Principles for Universal Access in addition to important Disability Access safeguards. UCPA responds also to issues raised in AFB's comments, particularly as they address affordability.

UCPA is a national nonprofit membership association of 156 affiliates in 44 states that delivers in excess of \$400 million of services annually to individuals with disabilities, including many persons with cerebral palsy and similar developmental disabilities. Significantly, two-thirds of individuals with cerebral palsy experience speech disabilities, typically with little or no clear speech. UCPA members are very familiar with the difficulties encountered by persons with speech disabilities as they attempt to utilize existing voice-based telephony. We believe that the telecommunications industry, under the new regulatory regime of P.L. 104-104, must address speech disability in development of principles for universal service so that barriers to communication will fall.

***On behalf of all persons with cerebral palsy and similar severe disabilities, UCPA urges inclusion of the access needs of persons with speech and other disabilities as a principle in developing universal service because (I) persons with disabilities are often among the poorest in the nation and (II) because the new telecommunications act clearly establishes that such needs are to be addressed both in principle and in practice.***

**I. ACCESS NEEDS OF LOW INCOME CONSUMERS MUST BE ADDRESSED AND WHICH INCLUDES PERSONS WITH DISABILITIES.**

UCPA notes that the Joint Board and the Commission shall base its policies on several factors according to the requirements of *Sec. 254 Universal Service, (B) UNIVERSAL SERVICE PRINCIPLES*:

*"(3) access in rural and high cost areas.-Consumers in all regions of the nation, including low-income consumers and those in rural, insular, and high cost areas, should have access to telecommunications and information services, including interexchange services and advanced telecommunications and information services, that are reasonably comparable to those services provided in urban areas and that are available at rates that are reasonably comparable to rates charged for similar services in urban areas."*

Although disability is not an indicator of poverty, UCPA reminds the Commission and the Joint Board to note that consumers with disabilities are among the poorest in the nation. Only 23.2 percent of persons with severe disabilities who are working aged (ages 21 to 64) are employed. The unemployment rate among those who are "unable to see words and letters" is 75 percent. Among those who are "unable to hear a normal conversation" 42 per cent are unemployed. And among those with severe speech disability or "unable to have speech understood" 76 percent are unemployed. [See Appendix II, tables from "Americans with Disabilities 1991-92", by the "U.S. Department of Commerce Economics & Statistics Administration, Bureau of the Census report, 1993 and Fact Sheet on Cerebral Palsy from United Cerebral Palsy Medical Foundation showing number of persons with cerebral palsy.]

Furthermore, a General Accounting Office (GAO) study released on September 10, 1992 indicated that families headed by a member with a disability remain among the poorest in the nation. While families headed by a member with a disability represent 4.5 percent of all poor families in 1988, their poverty rate remains the highest, at 45 percent. Family composition also has a major effect on poverty status: married-couple families without children headed by a person with a disability experience a poverty rate of 18 percent, but single-parent families headed by a person with a disability had a poverty rate of 67 percent, according to these 1988 Bureau of the Census figures. There has been an increase in the number of these families with children who are headed by a single parent with a disability, from 380,000 in 1980 to 421,000 in 1988, and current population trends indicate that this rate is continuing.

Although presence of disability is not an indicator of poverty, it is clear that millions of persons with disabilities live in low-income households. As universal service addresses affordability for all households that are low income, UCPA agrees with AFB that the access needs of low-income persons with disabilities must also be considered.

**UCPA therefore urges the Commission and the Joint Board to determine and include as an ADDITIONAL PRINCIPLE<sup>/1</sup>, as permitted by Sec. 254 (B) (7) of P.L. 104-104, the access needs of persons with disabilities as they develop policy for Universal Service.**

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<sup>/1</sup> (7) ADDITIONAL PRINCIPLES.-SUCH OTHER PRINCIPLES AS THE JOINT BOARD AND THE COMMISSION DETERMINE ARE NECESSARY AND APPROPRIATE FOR THE PROTECTION OF THE PUBLIC INTEREST, CONVENIENCE, AND NECESSITY AND ARE CONSISTENT WITH THIS ACT.

## II. ACCESS NEEDS OF INDIVIDUALS WITH DISABILITIES ALREADY ESTABLISHED AS A PRINCIPLE WITHIN THE NEW TELECOMMUNICATIONS ACT.

The access needs of individuals with disabilities have historically not been addressed in the Communications Act. The newly revised Act, in three additional Sections ("Sec. 255. *Access by Persons with Disabilities*", "Sec. 256 *Coordination for Interconnectivity*", and "Sec. 305. *Video Programming Accessibility*") clearly validates that these needs are to be addressed and in two instances, that is in Sec. 305 in the requirements for closed captioning and video description, indicates exactly how these are to be addressed as Inquiries.

Furthermore, the language of Section 255 uses, as its basis, the principles found in P.L. 101-336, The Americans With Disabilities Act, by (A) using *the definition of persons with disabilities*<sup>2</sup> and (B), within the framework for development of guidelines and standards development -- required at *Sec. 255 (a) E Guidelines* -- uses the "*if readily achievable*" criterion<sup>3</sup> for purposes of developing regulations. Similarly the requirements for access in video programming in Sec. 305 utilize ADA's "*undue burden*" criteria and establishes the scope of this standards requirement based on parameters found in ADA's regulatory scheme for assessing undue burden.

Use of these terms clearly establishes the ADA's principle of nondiscrimination on the basis of disability as one of the cornerstones in any principles that should be upheld wherever principles are to be addressed in additional sections of P.L. 104-104.

UCPA notes that within the *Findings* section of the ADA, discrimination against individuals with disabilities is identified as persisting in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services. The nation's telecommunications systems are a vital infrastructure providing the means to securing these aspects of a regular life.

Likewise, within the *Purposes* of the ADA are included stipulations (i) providing for clear, strong consistent, enforceable standards, (ii) ensuring that the Federal Government plays a central role, and (iii) including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities. [see Appendix III for full text of ADA's Findings and Purposes.]

**UCPA therefore urges the Commission and the Joint Board to include as an ADDITIONAL PRINCIPLE, the underlying principle of inclusion of persons with disabilities as they develop principles and policy for Universal Service in order to be consistent with principles already invoked by the new Telecommunications Act.**

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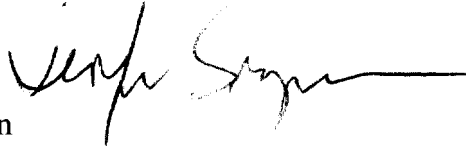
<sup>2</sup> "SEC. 255. ACCESS BY PERSONS WITH DISABILITIES. "(a) DEFINITIONS.-AS USED IN THIS SECTION- (1) DISABILITY.-THE TERM 'DISABILITY' HAS THE MEANING GIVEN TO IT BY SECTION 3(2)(A) OF THE AMERICANS WITH DISABILITIES ACT OF 1990 (42 U.S.C. 12102(2)(A)).

<sup>3</sup> (2) READILY ACHIEVABLE.-THE TERM 'READILY ACHIEVABLE' HAS THE MEANING GIVEN TO IT BY SECTION 301(9) OF THAT ACT (42 U.S.C. 2181(9)).

**UCPA requests, therefore, that the Joint Board consider broad interpretation of such terms as "access", "useability" and "affordability" in development of Universal Service principles. Barriers to access, usability and affordability in telecommunications services must fall for persons with functional differences in speech, hearing, vision, movement, manipulation, and interpretation of information across the age spectrum for universal service to truly reach all Americans.**

UCPA would be happy to discuss these comments.

Sincerely,

A handwritten signature in black ink, appearing to read 'Jenifer Simpson', with a long horizontal flourish extending to the right.

Jenifer Simpson  
Policy Associate  
Community Services Division

Attachments

## **APPENDIX I A**

**COPY OF REPLY COMMENTS TO FCC IN DOCKET NO. 80-286  
ON UNIVERSAL SERVICE PREVIOUSLY SUBMITTED**





UNITED  
CEREBRAL  
PALSY  
ASSOCIATIONS

*Advancing the independence of people with disabilities*

December 2, 1994 COPY

Office of the Secretary  
Federal Communications Commission  
1919 M Street, N.W.,  
Washington, D.C. 20554

**Re: Docket No. 80-286 -- Reply Comment to Notice of Inquiry  
REQUEST FOR INCLUSION OF ACCESS BY PERSONS WITH  
DISABILITIES IN THE DISCUSSION ON UNIVERSAL SERVICE**

Dear Secretary and Commissioners:

United Cerebral Palsy Associations (UCPA) appreciates the opportunity to offer Reply Comments concerning the FCC proceeding in the matter of Amendment of Part 36 of the Commission's Rules and Establishment of a Joint Board [Docket No. 80-286]. We were unaware of this proceeding until recently but note that inclusion of the needs of individuals with disabilities has been omitted so far.

UCPA is particularly disturbed at this omission as our concerns were directed to the FCC in April 1994 when a discussion on new general principles for universal service was initiated. A copy of our letter to Dr. Jorge Schement is attached. Our comments today address this serious omission and will further the discussion.

**UCPA Recommendation for Expansion of Discussion**

UCPA is highly interested in this proceeding and asks the FCC to broaden its inquiry to include access for individuals with disabilities. We recommend:

- Expansion of the scope of the discussion in the current consideration of universal services to include the technology and affordability needs of individuals with disabilities; and to not move forward in making any changes to the current Universal Service fund until more careful consideration has been given to the full range of issues in making telephone service available to all Americans, which includes individuals with functional differences in speech, hearing, vision, motor and cognitive abilities.
- Inclusion of universal design principles in any broadened discussion about the universal services fund.

**UCPA Familiar With Speech Disability Population**

UCPA is a leading national not-for-profit health related association of more than 155 affiliates in 43 states delivering in excess of \$400 million of services annually. UCPA

extends services to and advocates on behalf of children and adults with cerebral palsy and those with similar disabilities, and their families, to assist such individuals in becoming full community members. In addition, currently about 5,000 babies and infants are diagnosed with cerebral palsy each year, and approximately 1,200 to 1,500 pre-school age children acquire cerebral palsy annually.

Cerebral palsy is a term used to describe a group of chronic conditions affecting body movement and muscle coordination and is not a disease or illness or an indicator of cognitive ability. **Significantly, two-thirds of individuals with cerebral palsy experience speech disabilities, typically with no or little clear speech.**

#### **UCPA's Concern For Those With Speech Disabilities**

Overall, there are estimated to be about 3 million Americans with significant speech disabilities and up to 14 million who may experience or acquire temporary or permanent speech limitations as a result of injury or trauma. Many of these individuals experience difficulties utilizing telephony, an instrument critical in productivity, integration and independence, and safety, for all Americans. UCPA is particularly concerned with the provision of access to the voice based telephone networks for individuals with significant speech disabilities who experience disconnection or lack of service when they utilize current telephony. Hang-up on speech-disabled callers occurs in making long-distance calls, when utilizing 411 or 911 services and in routine conducting of business or personal matters by individuals who use Augmentative or Alternative Communication (AAC) devices, or who use other electronic or synthetic voice generators.

#### **Current Technological Changes Must be Addressed in Universal Services Discussion**

The telecommunications system is rapidly changing and new technologies make it possible to make network services and equipment that is useable by a broader range of telephone consumers than ever before. There is the capability to build accessibility into the network, and to universally design telecommunications equipment and network services to address a wider scope of human sensory and functional parameters. For example, voice dialing or activation systems permit people with severe mobility limitations to use telephones and proposed future two-way interactive video telephones could enable people with hearing disabilities to see sign language calls or to lip-read. UCPA urges that in any discussion about universal service a universal design approach must be incorporated

#### **Consider Universal Design Principles in Fund Application**

Universal design means thinking through, during the design process itself, and before marketing, how individuals with all different kinds of disabilities might utilize the product or service. For development of advanced telecommunications which utilize telephony this would further making all products and services user-friendly as universal design would address functional differences in hearing, vision, speech, motor ability and manipulation of information as the human parameters for technological interoperability.

Typically, add-ons or specialized equipment designed as an afterthought in product or services development is no longer a useful, economic or efficient approach and often creates unnecessary expense to consumers and others. UCPA notes the cost burden of specialized equipment currently is shifted onto persons with disabilities, and their families, and may often include public funding of specialized adaptive equipment. For instance, a digitally based AAC device can cost as much as \$10,000 for one individual. Much of that 'intelligence' could be built into the network to be shared by multiple users with speech disabilities, perhaps utilizing devices that cost one tenth of this cost. The universal services fund should address this potential technological development.

Additionally, individuals with disabilities often find themselves as being in the position of playing catch up with the latest technology and this is neither fair or cost-conscious from a universal services approach.

For a person with significant speech disability, a universal design approach could permit creation of a



standard indicator, such as a recognizable electronic tone or sound for instance, that lets a call recipient know that the voice is that of a real person, simply generated from an AAC device, and not a pre-taped advertising message, eliminating the frustration and exclusion from telephone conversation that disconnection causes. The universal services fund could permit such systemic development to expand network services and could permit greater provision of equipment for individuals with disabilities.

**Conclusion**

UCPA believes that if the Commission were to widen its discussion of the universal services fund to include a universal design approach there may be created great and shared opportunities to tap the vast human resources of the disability community.

UCPA would be happy to discuss the policy issues underlying our comments.

Sincerely,

Jenifer Simpson  
Policy Associate  
Community Services Division

## **APPENDIX I B**

**Attachment to Previous letter  
on DEVELOPING NEW GENERAL PRINCIPLES FOR UNIVERSAL SERVICE  
-- *The Disability Perspective***



UNITED  
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PALSY  
ASSOCIATIONS

*Advancing the independence of people with disabilities*

April 20, 1994                      COPY

Dr. Jorge Schement  
Federal Communications Commission  
1919 M Street, N.W.  
Washington, DC 20036

**Re:    DEVELOPING NEW GENERAL PRINCIPLES FOR UNIVERSAL  
SERVICE -- *The Disability Perspective***

Dear Dr. Schement:

As you may already know, individuals with disabilities are greatly interested in the rapidly changing electronic communications environment and how these changes will affect their lives, particularly in the areas of technical access and affordability, and what a new definition of *Universal Service* would look like. I very much appreciated your discussion at the Telecommunications Policy Roundtable meeting on April 5, with your associate Larry Povich, which opened the FCC's discussion on this critical concept.

At United Cerebral Palsy Associations (UCPA) our national volunteer committee for Governmental Activities & Advocacy has made **telecommunications** one of UCPA's legislative (and regulatory) priorities for the 103rd Congress. UCPA is a national not-for-profit disability services organization whose 150 affiliates in 44 states deliver in excess of \$400 million annually of direct and advocacy services to children, youth and adults with disabilities, including disabilities as a result of cerebral palsy.

In my role as co-chair of the Consortium For Citizens With Disabilities (CCD) Task Force on Communications Access/Telecommunications, I assisted in developing the "***Disability Perspective: Several Principles of Communications Access With Regard to the Electronic Information and Communications Infrastructure***," which asserts that **NONDISCRIMINATION, COMPREHENSIVENESS, EFFECTIVENESS, EQUITY, AFFORDABILITY** and **EMPLOYMENT** are critical principles within the disability community in terms of access and universality issues. CCD's policy statement on these principles will assist you in developing the new general principles for Universal Service (statement attached).

Additionally, UCPA has developed two policies on communications issues that you

may find useful as well in the development of general principles for universal service. Enclosed are:

- UCPA Policy Statement on Communications Accessibility: "*Towards an all Inclusive Definition of Communications Accessibility*"; and
- "*Free Speech Rights of Americans With Disabilities.*"

I would like to meet with you to discuss the concepts and ideas undergirding CCD's and UCPA's enclosed statements as you develop a new concept of *Universal Service*. Please do not hesitate to contact me at (202) 842-1266.

Regards,

Jenifer Simpson  
Policy Associate  
Community Services Division

cc: Larry Povich, FCC

## **APPENDIX I C**

### **Attachment To Previous Letter**

#### **UCPA Policy Statements**

- **UCPA Policy Statement on Communications Accessibility:** "*Towards an all Inclusive Definition of Communications Accessibility*"; and
- **UCPA Resolution on** "*Free Speech Rights of Americans With Disabilities.*"

## UCPA POLICY STATEMENT ON COMMUNICATIONS ACCESSIBILITY: "TOWARDS AN ALL INCLUSIVE DEFINITION OF COMMUNICATIONS ACCESSIBILITY"

- (A) *COMMUNICATIONS ACCESSIBILITY* - means making all expressive and receptive communications accessible to persons with disabilities, and recognizes that every individual is (1) capable of communicating, and (2) knows best how to convey his or her thoughts to others; and (3) extends the same basic common courtesies of interacting with people with disabilities that are extended to others in receiving the goods, services, facilities, privileges, advantages, or accommodations offered by an entity providing such services by;
- Affording such individuals with the necessary opportunity, auxiliary aids and supports to effectively communicate with others. In determining what type of auxiliary aid is necessary, an entity shall give primary consideration to the requests of the individual with disabilities. [See Endnote below.]
  - Providing a communications environment which allows and encourages persons with motor, cognitive, hearing, speech or vision disabilities to effectively express themselves, understand others, and/or receive or send information and signals over public alert, public address and telecommunications systems and networks;
  - Providing individuals with disabilities the assistive technology, interpretive services and personal assistance each needs to communicate effectively with others.

Such a definition would also recognize communications access as an issue that impacts individuals with a variety of disabilities other than hearing impairment and therefore to expand any definition of access with an added reference to

"augmentative communication devices, computer modem access via the telephone lines, or other effective methods of making communication available to individuals with hearing or speech impairments" whenever TTDs/TTs are listed as a device. An explanation of communications accommodation should also be included in any definition:

- (B) *Accommodation (by an entity)* means taking the time to communicate to a person with limited speech or who is using a manual communication board or assistive device; speaking and responding directly to such an individual rather than any third party unless directed otherwise (to the extent practical, this should apply to children and adults); not hanging up on or refusing telephone inquiries from such individuals or not forcing someone to write everything out on a note pad if he or she does not want to communicate in this fashion; or not inferring or implying that just because an individual has limited natural speech that he or she also has limited or impaired intelligence, hearing or judgment.

A list that includes examples of assistive devices that could be a reasonable accommodation to someone with cerebral palsy or other severe physical disability would look like the following:

- (C) *The following lists examples of assistive technology devices that could be a reasonable accommodation to someone with cerebral palsy or other severe physical disability and includes but is not limited to:* Remote control switches for use of computers and other office equipment; adaptive switches to turn on/off lights; telephone adaptations such as speaker phones, headsets, modems, TDDs or TTs (text telephones); reachers; simple adaptations/fixtures for using office machines; magnifiers; adjustable furniture; adaptive computer software; page turners; lever door handles; access to a regular computer or typewriter to fill out forms; communication boards; telephones with audio and data transmission capability; telephones with wireless audio and data communication capabilities; augmentative communication devices; automated interpreters; computer and computer modem access in commonly used access forms such as ASCII; voice recognition systems; voice activated telephones; pointing and typing aids such as headpointers and mouthsticks; alternative switches to control lights and elevator doors and other access devices; electronic equipment which can be activated by sipping, puffing, movement of the eye, head, wrist, finger, or by remote or wireless means; alternative keyboards; keyguards; large button telephones; automatic dialing, and other effective and efficient methods of assuring reasonable accommodation and access to telecommunication networks, switching services and similar services that allow an individual with a disability to enjoy the same benefits and privileges of services that are made available to individuals without speech, mobility or manual dexterity impairments.

**Endnote:** Congress has already recognized that individuals with disabilities are in the best position to identify the appropriate auxiliary aid in a given context. See 28 CFR Sec. 39.160(b) and the ADA Conference Report No. 101-116, which states that the "expressed choice" of an individual with a disability for an effective accommodation shall be given "primary consideration"; the HHS Office for Civil Rights also has a long-standing policy granting a "presumption favoring the hearing-impaired individual's self-assessed need" for a particular type of auxiliary aid. (Memorandum from Roma J. Stewart, Director, Office for Civil Rights, dated April 21, 1980).

**ADOPTED BY THE UCPA GOVERNMENTAL ACTIVITIES & ADVOCACY COMMITTEE, JANUARY 26, 1992, AND BY THE UCPA BOARD OF DIRECTORS, APRIL 4, 1992.** United Cerebral Palsy Associations, Inc., 1522 K Street, N.W., Suite 1112, Washington, DC 20005. (800) USA-5UCP or (202) 842-1266; Contact-Jenifer Simpson or Bob Williams.

UCPA SUPPORTS RIGHT OF INDIVIDUALS WITH SPEECH DISABILITIES TO FREE SPEECH AND COMMUNICATIONS ACCESSIBILITY

**FREE SPEECH RIGHTS OF AMERICANS WITH DISABILITIES**

- December 15, 1991 marked the bicentennial of the ratification of the Bill of Rights and its First Amendment guarantee to free speech. In the two hundred years since adoption of the first Amendment, freedom of expression has become widely recognized, not only as a fundamental right but also as a prerequisite to the full enjoyment of all civil and human rights. However, for far too many Americans with significant speech disabilities, freedom of expression remains an unrealized right at best: an American ideal which has yet to be fulfilled.
- An estimated 750,000 to 1.5 million Americans of all ages have severely limited speech which cannot be easily understood. Approximately **30 percent of persons with cerebral palsy** are in this group, and 85 to 90 percent of all individuals with cerebral palsy have a speech disability of one kind or another.
- Freedom of expression is both a necessity and a highly prized right in our country. In its absence Americans with significant speech disabilities routinely experience isolation, discrimination, segregation, illiteracy, institutionalization, unemployment, poverty and despair. Due to the lack of understandable speech, these individuals are perceived to be unable to direct their own lives: a perception that often leads to an erosion or outright deprivation of their most basic civil rights and liberties. This "cloak of incompetence" is the heaviest burden Americans with significant speech disabilities have always faced in our country, and now is the time to cast off this cloak once and for all.
- The Americans With Disabilities Act (ADA) and Section 504 of the Rehabilitation Act reaffirm that individuals with disabilities, like all other citizens of our land, have a right to free speech and effective communication. Increasing access to alternative and augmentative means of communication and related assistive technology can and should provide expanded opportunities for individual choice and control.
- Prevailing governmental policies, practices and ingrained societal prejudices combine to limit and prevent Americans with severe speech disabilities from obtaining appropriate technology and exercising their right to free expression. Individual access to alternative and augmentative communication technology and the exercise of free speech, more often than not, continue to be treated as a luxury rather than a right.

**UNITED CEREBRAL PALSY ASSOCIATIONS, INC.** should commit itself to mobilizing persons with speech disabilities to work in close alliance with our families, friends and all other supporters of the First Amendment throughout the Nation to realize free expression as a real individual right by:

*identifying and working to eliminate governmental practices and societal prejudices which prohibit Americans with speech disabilities from exercising our individual right to free expression; and seeking to identify and reverse Federal Policies that have a disparate impact on the abilities of Americans with Disabilities to exercise their free speech and effective communication rights.*

**UNITED CEREBRAL PALSY ASSOCIATIONS, INC.** calls upon the President, Members of Congress and the Executive Branch to assure the guarantees of free speech to all Americans, including individuals with communication disabilities by,

- ensuring that the free speech, rights of redress and the effective communication requirements of Titles II and IV of The Americans With Disabilities Act and Section 504 of the Rehabilitation Act are rigorously adhered to by all Federal, State and local governmental entities;
- requiring policies and practices that may limit or prohibit the free speech rights of such individuals to undergo the strictest scrutiny in order to take or remain in effect;
- developing and adopting a Federal definition of and necessary standards for "communication



accessibility" to better assure that all Americans with disabilities can exercise their full individual right to free speech, redress and effective communication as guaranteed them by the First Amendment, the Americans with Disabilities Act and Section 504 of the Rehabilitation Act;

**ADOPTED BY THE GOVERNMENTAL ACTIVITIES & ADVOCACY COMMITTEE, JANUARY 26, 1992, AND BY THE UCPA BOARD OF DIRECTORS, APRIL 4, 1992.**

## **APPENDIX II**

### **Information on Cerebral Palsy from the United Cerebral Palsy Medical Foundation**

and from

### **Selected Tables from Census Report on 1992 Disabilities**



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## ***Cerebral Palsy - Facts & Figures***

### **What is cerebral palsy?**

Cerebral palsy is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during fetal development; before, during or shortly following birth; or during infancy. "Cerebral" refers to the brain and "palsy" to muscle weakness/poor control. Cerebral palsy itself is not progressive (*i.e.*, it does not get worse); however, secondary conditions can develop which may get better over time, get worse, or remain the same. Cerebral palsy is not communicable. It is not a disease and should never be referred to as such. Although cerebral palsy is not "curable" in the accepted sense, training and therapy can help improve function.

### **What are the effects?**

Cerebral palsy is characterized by an inability to fully control motor function, particularly muscle control and coordination. Depending on which areas of the brain have been damaged, one or more of the following may occur: muscle tightness or spasm; involuntary movement; disturbance in gait and mobility. In addition, the following may also occur: abnormal sensation and perception; impairment of sight, hearing or speech; seizures; and mental retardation. Other problems that may arise are difficulties in feeding, bladder and bowel control, problems with breathing because of postural difficulties, skin disorders because of pressure sores, and learning disabilities.

### **What are the causes?**

A large number of factors which can injure the developing brain may produce cerebral palsy. One important cause is an insufficient amount of oxygen reaching the fetal or newborn brain. Oxygen supply can be interrupted by premature separation of the placenta from the wall of the uterus, awkward birth position of the baby, labor that is too long or too abrupt, or interference with circulation in the umbilical cord. Premature birth, low birth weight, RH or A-B-O blood type incompatibility between mother and infant, infection of the mother with German measles or other virus diseases in early pregnancy, and microorganisms that attack the infant's central nervous system also are risk factors for cerebral palsy. Most causes of cerebral palsy are related to the developmental and childbearing processes and, since the condition is not inherited, the condition is often called *congenital cerebral palsy*. A less common type is *acquired cerebral palsy*, usually occurring before two years of age. Head injury is the most frequent cause, usually the result of motor vehicle accidents, falls, or child abuse; another cause is brain infection.

### **Are there different types of cerebral palsy?**

There are three main types: spastic -- stiff and difficult movement; athetoid -- involuntary and uncontrolled movement; ataxic -- disturbed sense of balance and depth perception. There may be a mixture of these types for any individual. Other types do occur, although infrequently.

### **How many people have cerebral palsy?**

It is estimated that some 500,000 children and adults in the United States manifest one or more of the symptoms of cerebral palsy. Currently about 5,000 babies and infants are diagnosed with the condition each year. In addition, some 1,200 - 1,500 preschool age children annually are recognized to have cerebral palsy.

### **Can it be prevented?**

Yes. Measures of prevention are increasingly possible today. Pregnant women are tested routinely for the Rh factor and, if Rh negative, they can be immunized within 72 hours after the birth (or after the pregnancy terminates) and thereby prevent adverse consequences of blood incompatibility in a subsequent pregnancy. If the woman has not been immunized, the consequences of blood incompatibility in the newborn can be prevented by exchange transfusion in the baby. If a newborn baby has jaundice, this can be treated by phototherapy in the hospital nursery. Other preventive programs are directed toward the prevention of prematurity; reducing exposure of pregnant

women to virus and other infections; unnecessary exposure to X-rays, drugs and medications; and the control of diabetes, anemia and other nutritional deficiencies. Of great importance are optimal well being prior to conception, adequate prenatal care, and protecting infants from accidents or injury.

### **Can cerebral palsy be treated?**

“Management” is a better word than “treatment.” Management consists of helping the child achieve maximum potential in growth and development. This should be started as early as possible with identification of the very young child who may have a developmental disorder. A management program can then be started promptly to include attention to the child’s movement, learning, speech, hearing, and social and emotional development. In these programs, physicians, therapists, educators, nurses, social workers, and other professionals assist the family as well as the child. Certain medications, surgery, and braces may be used to improve nerve and muscle coordination and prevent dysfunction.

As individuals mature, they may require support services such as personal assistance services, continuing therapy, educational and vocational training, independent living services, counseling, transportation, recreation/leisure programs, and employment opportunities, all essential to the developing adult. People with cerebral palsy can go to school, have jobs, get married, raise families, and live in homes of their own. Most of all, people with cerebral palsy need the opportunity for independence and full inclusion in our society.

### **Is research being done on cerebral palsy?**

Yes. Active national programs of research are being vigorously pursued to prevent cerebral palsy and to improve the quality of life for persons with cerebral palsy. The two organizations with major research programs are the United Cerebral Palsy Research and Educational Foundation in the private sector and the National Institutes of Health in the government sector. The research questions being addressed include:

- What are the factors that predispose the developing fetal brain to injury? Can these factors be eliminated or minimized?
- What are the causes of lack of oxygen and of growth factors to the developing fetal brain? Can the developing fetal and newborn brain be protected?
- Why are low birth weight in the full-term infant and prematurity important risk factors for cerebral palsy?
- Can cerebral palsy be diagnosed before birth and better diagnosed shortly after birth?
- Which available treatments are most effective for specific disabilities of persons with cerebral palsy?
- Based on new knowledge now available in the medical, surgical, behavioral and bioengineering sciences, what improvements can be made in the quality of life of people with cerebral palsy?
- What are the effects of aging on a person with cerebral palsy?

### **What is United Cerebral Palsy Associations?**

Founded in 1949, United Cerebral Palsy Associations is a nationwide network of 155 state and local voluntary agencies (UCP affiliates) which provides programs and services and conducts public and professional education programs relevant to cerebral palsy and other disabilities. Direct services provided by United Cerebral Palsy affiliates to children and adults with cerebral palsy and other disabilities and their families include medical diagnosis, evaluation and treatment; therapy; assistive technology; information and referral; early intervention; employment; individual and family support; social and recreation programs; community inclusion and independent living; advocacy and community education. More than 30,000 people with cerebral palsy and other disabilities and their families receive assistance from UCP affiliates each day. United Cerebral Palsy Associations is the largest health charity in America and is also one of the most efficient with its funds. *MONEY* magazine has rated UCPA as one of America’s Top Five health charities several years in a row, with more than 85 percent of its funds spent directly on programs and services. In *Kiplinger’s Personal Finance Magazine’s* ranking of America’s 100 most efficient charities, United Cerebral Palsy was one of only 16 of the 100 organizations listed to receive the highest ranking of A or better from the American Institute of Philanthropy, a charity watchdog group.

### **What is the United Cerebral Palsy Research and Educational Foundation?**

The UCP Research and Educational Foundation is the nation’s principle non-government agency sponsoring research directly relevant to the prevention of cerebral palsy and improvement in the quality of life of persons with disabilities due to cerebral palsy and related developmental disorders. In its 35 year history, the Foundation has been instrumental in eliminating two of the major causes of cerebral palsy: german measles and maternal-child blood type incompatibility. The Foundation is now focusing its attention on the remaining major causes such as low birth weight, prematurity, and the effects of poor oxygenation on the developing brain. It is exploring also the development of improved methods for mobility, communication and the general well being of children and adults with developmental disorders of the brain. The Foundation’s programs support the exploration of innovative ideas with funds for pilot projects and serves as a source of funds to explore new opportunities.

women to virus and other infections; unnecessary exposure to X-rays, drugs and medications; and the control of diabetes, anemia and other nutritional deficiencies. Of great importance are optimal well being prior to conception, adequate prenatal care, and protecting infants from accidents or injury.

## **Can cerebral palsy be treated?**

“Management” is a better word than “treatment.” Management consists of helping the child achieve maximum potential in growth and development. This should be started as early as possible with identification of the very young child who may have a developmental disorder. A management program can then be started promptly to include attention to the child’s movement, learning, speech, hearing, and social and emotional development. In these programs, physicians, therapists, educators, nurses, social workers, and other professionals assist the family as well as the child. Certain medications, surgery, and braces may be used to improve nerve and muscle coordination and prevent dysfunction.

As individuals mature, they may require support services such as personal assistance services, continuing therapy, educational and vocational training, independent living services, counseling, transportation, recreation/leisure programs, and employment opportunities, all essential to the developing adult. People with cerebral palsy can go to school, have jobs, get married, raise families, and live in homes of their own. Most of all, people with cerebral palsy need the opportunity for independence and full inclusion in our society.

## **Is research being done on cerebral palsy?**

Yes. Active national programs of research are being vigorously pursued to prevent cerebral palsy and to improve the quality of life for persons with cerebral palsy. The two organizations with major research programs are the United Cerebral Palsy Research and Educational Foundation in the private sector and the National Institutes of Health in the government sector. The research questions being addressed include:

- What are the factors that predispose the developing fetal brain to injury? Can these factors be eliminated or minimized?
- What are the causes of lack of oxygen and of growth factors to the developing fetal brain? Can the developing fetal and newborn brain be protected?
- Why are low birth weight in the full-term infant and prematurity important risk factors for cerebral palsy?
- Can cerebral palsy be diagnosed before birth and better diagnosed shortly after birth?
- Which available treatments are most effective for specific disabilities of persons with cerebral palsy?
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SIMPSON

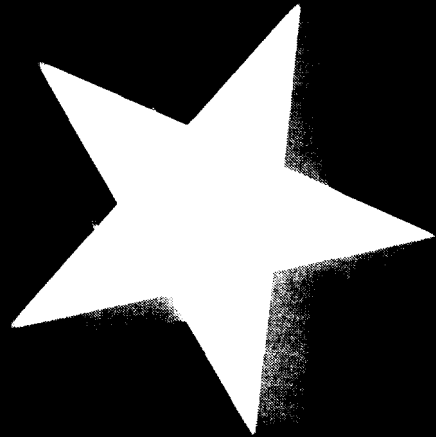


CURRENT POPULATION REPORTS  
**Household Economic Studies**

P70-33

**Americans With  
Disabilities: 1991-92**

Data From the  
Survey of Income  
and Program  
Participation



by John M. McNeil

U.S. Department of Commerce  
Economics and Statistics Administration  
BUREAU OF THE CENSUS

working age

Table 24. Employment Status of Persons 21 to 64 Years Old, by Sex and Type of Disability: 1991-92

Numbers in thousands]

Characteristic	Both sexes			Males			Females		
	Total	Employed		Total	Employed		Total	Employed	
		Number	Percent		Number	Percent		Number	Percent
PERSONS 21 TO 64 YEARS OLD									
Total .....	144,778	108,684	75.1	70,923	58,975	83.2	73,855	49,709	67.3
With no disability .....	117,194	94,347	80.5	57,506	51,045	88.8	59,688	43,301	72.6
With a disability .....	27,584	14,337	52.0	13,418	7,930	59.1	14,167	6,408	45.2
Severe .....	12,568	2,921	23.2	5,549	1,327	23.9	7,019	1,594	22.7
Not severe .....	15,016	11,416	76.0	7,869	6,603	83.9	7,148	4,814	67.3
With a functional limitation .....	18,098	8,789	48.6	8,503	4,781	56.2	9,596	4,008	41.8
Severe .....	6,397	1,766	27.6	2,595	733	28.3	3,802	1,033	27.2
Seeing words and letters .....	4,576	2,086	45.6	2,078	1,107	53.3	2,497	979	39.2
Unable .....	563	144	25.6	268	83	30.9	296	61	20.8
Hearing normal conversation .....	5,241	3,335	63.6	3,467	2,395	68.8	1,774	951	53.6
Unable .....	324	189	58.2	221	139	62.8	103	50	48.4
Having speech understood .....	1,346	469	34.9	786	300	38.1	560	169	30.3
Unable .....	122	30	24.4	79	22	27.2	43	8	19.4
Lifting and carrying 10 lbs .....	7,606	2,436	32.0	2,656	867	32.7	4,949	1,569	31.7
Unable .....	3,028	674	22.3	1,036	186	18.0	1,992	488	24.5
Climbing stairs without resting .....	7,852	2,359	30.0	3,123	1,027	32.9	4,728	1,332	28.2
Unable .....	3,516	722	20.5	1,366	293	21.4	2,150	429	20.0
Walking 3 city blocks .....	7,720	2,426	31.4	3,308	1,145	34.6	4,413	1,281	29.0
Unable .....	3,182	660	20.8	1,291	260	20.2	1,891	400	21.2
Number of functional limitations:									
1 .....	9,273	5,911	63.8	4,729	3,376	71.4	4,544	2,535	55.8
2 .....	3,812	1,779	46.7	1,739	918	52.8	2,074	860	41.5
3 or more .....	5,013	1,099	21.9	2,036	466	23.9	2,978	613	20.6
Number of severe functional limitations:									
1 .....	3,520	1,271	36.1	1,471	535	36.3	2,049	736	35.9
2 .....	1,566	357	22.8	632	157	24.8	934	200	21.5
3 or more .....	1,311	139	10.6	491	42	8.6	820	97	11.8
With an ADL limitation .....	3,336	841	25.2	1,474	412	27.9	1,862	429	23.1
Needs personal assistance .....	1,455	263	18.1	652	123	18.9	802	140	17.5
Getting around inside the home .....	1,253	173	13.8	556	79	14.2	697	94	13.5
Needs personal assistance .....	555	57	10.3	254	27	10.5	301	30	10.1
Getting in or out of bed or a chair .....	2,327	582	25.0	1,033	295	28.6	1,294	286	22.1
Needs personal assistance .....	841	151	17.9	387	68	17.6	454	83	18.2
Taking a bath or shower .....	1,540	254	16.5	606	80	13.2	934	175	18.7
Needs personal assistance .....	856	109	12.8	381	40	10.4	475	70	14.7
Dressing .....	1,275	233	18.3	565	104	18.5	710	129	18.1
Needs personal assistance .....	739	119	16.1	353	57	16.3	386	61	15.9
Eating .....	405	88	21.7	184	43	23.2	220	45	20.4
Needs personal assistance .....	138	22	15.8	68	14	20.5	71	8	11.4
Using the toilet, including getting to the toilet .....	690	122	17.7	295	60	20.2	395	62	15.8
Needs personal assistance .....	363	48	13.3	160	30	18.7	203	19	9.2
Number of ADL limitations:									
1 .....	1,535	520	33.9	713	287	40.2	822	234	28.5
2 .....	682	170	24.9	288	59	20.7	394	110	28.0
3 or more .....	1,118	151	13.5	473	65	13.7	676	85	13.2
Number of ADL's for which personal assistance needed:									
1 .....	566	139	24.6	224	67	30.1	342	72	21.0
2 .....	360	61	16.9	193	27	13.9	167	34	20.3
3 or more .....	528	63	11.9	235	29	12.3	294	35	11.9

**Table 24. Employment Status of Persons 21 to 64 Years Old, by Sex and Type of Disability:  
1991-92—Continued**

Numbers in thousands]

Characteristic	Both sexes			Males			Females		
	Total	Employed		Total	Employed		Total	Employed	
		Number	Percent		Number	Percent		Number	Percent
With an IADL limitation .....	4,834	1,106	22.9	2,093	517	24.7	2,741	589	21.5
Needs personal assistance ...	3,395	661	19.5	1,397	258	18.5	1,998	402	20.1
Going outside the home, for example to shop or visit a doctor's office .....	2,764	417	15.1	1,164	172	14.8	1,600	246	15.4
Needs personal assistance ...	1,896	248	13.1	777	101	13.0	1,119	147	13.2
Keeping track of money and bills .....	1,464	285	19.5	741	155	21.0	723	130	17.9
Needs personal assistance ...	1,263	220	17.4	658	122	18.5	605	98	16.2
Preparing meals .....	1,576	229	14.5	638	89	14.0	938	140	14.9
Needs personal assistance ...	1,237	177	14.3	521	64	12.2	716	114	15.9
Doing light housework, such as washing dishes or sweeping a floor .....	2,459	425	17.3	934	147	15.8	1,525	278	18.2
Needs personal assistance ...	1,689	260	15.4	628	75	12.0	1,061	185	17.5
Using the telephone .....	1,044	298	28.5	624	204	32.6	419	94	22.4
Unable to use .....	334	90	27.1	202	51	25.0	288	54	18.8
Number of IADL limitations:									
1 .....	2,432	765	31.5	1,060	361	34.1	1,372	404	29.5
2 .....	1,108	196	17.7	465	85	18.2	643	111	17.2
3 or more .....	1,294	145	11.2	569	71	12.5	726	74	10.2
Number of IADL's for which personal assistance needed:									
1 .....	1,711	443	25.9	669	155	23.1	1,042	288	27.6
2 .....	797	135	17.0	330	67	20.3	467	68	14.6
3 or more .....	888	83	9.3	398	37	9.3	489	47	9.6
Uses a wheelchair .....	495	91	18.4	230	46	20.2	265	44	16.8
Does not use a wheelchair but has used a cane, crutches, or a walker for six months or longer ..	1,108	195	17.6	563	118	21.0	545	77	14.1
Needs personal assistance with an ADL or IADL .....	3,701	763	20.6	1,566	329	21.1	2,136	434	20.3
With a mental or emotional disability .....	4,529	1,947	43.0	2,353	1,066	45.3	2,177	880	40.5
Mental retardation .....	860	265	30.8	526	165	31.3	334	100	29.9
With a work disability .....	17,252	7,340	42.5	8,468	4,096	48.4	8,784	3,244	36.9
With a housework disability .....	9,377	3,021	32.2	4,185	1,418	33.9	5,193	1,603	30.9
Unable to do housework .....	1,193	165	13.8	667	104	15.6	526	61	11.6



## APPENDIX III

### P.L. 101-336, The Americans With Disabilities Act

#### 42 USC 12101 SEC. 2 FINDINGS AND PURPOSES.

(a) *FINDINGS- The Congress finds that-*

(1) *some 43,000,000 Americans have one or more physical or mental disabilities, and this number is increasing as the population as a whole is growing older;*

(2) *historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;*

(3) *discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;*

(4) *unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;*

(5) *individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criterion, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;*

(6) *census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;*

(7) *individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society;*

(8) *the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and*

(9) *the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.*

(b) *PURPOSE- It is the purpose of the Act-*

(1) *to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;*

(2) *to provide a clear, strong consistent, enforceable standards addressing discrimination against individuals with disabilities;*

(3) *to ensure that the Federal Government plays a central role in enforcing the standards established in this Act on behalf of individuals with disabilities; and*

(4) *to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.*